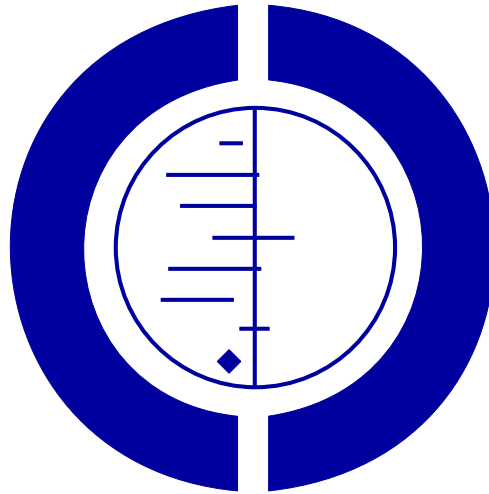


Parent-mediated early intervention for young children with autism spectrum disorder (Review)

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This record should be cited as:

Diggle T, McConachie H R, Randle V R L. Parent-mediated early intervention for young children with autism spectrum disorder. *The Cochrane Database of Systematic Reviews* 2002, Issue 2. Art. No.: CD003496. DOI: 10.1002/14651858.CD003496.

This version first published online: 22 April 2002 in Issue 2, 2002.

Date of most recent substantive amendment: 29 January 2002

ABSTRACT

Background

Recent estimates concerning the prevalence of autistic spectrum disorder are much higher than those reported 30 years ago, with at least 1 in 400 children affected. This group of children and families have important service needs. The involvement of parents in implementing intervention strategies designed to help their autistic children has long been accepted as helpful. The potential benefits are increased skills and reduced stress for parents as well as children.

Objectives

The objective of this review was to determine the extent to which parent-mediated early intervention has been shown to be effective in the treatment of children aged 1 year to 6 years 11 months with autistic spectrum disorder. In particular, it aimed to assess the effectiveness of such interventions in terms of the benefits for both children and their parents.

Search strategy

A range of psychological, educational and biomedical databases were searched. Bibliographies and reference lists of key articles were searched, field experts were contacted and key journals were hand searched.

Selection criteria

Only randomised or quasi-randomised studies were included. Study interventions had a significant focus on parent-implemented early intervention, compared to a group of children who received no treatment, a waiting list group or a different form of intervention. There was at least one objective, child related outcome measure.

Data collection and analysis

Appraisal of the methodological quality of included studies was carried out independently by two reviewers. Differences between the included studies in terms of the type of intervention, the comparison groups used and the outcome measures were too great to allow for direct comparison.

Main results

The results of this review are based on data from two studies. Two significant results were found to favour parent training in one study: child language and maternal knowledge of autism. In the other, intensive intervention (involving parents, but primarily delivered by professionals) was associated with better child outcomes on direct measurement than were found for parent-mediated early intervention, but no differences were found in relation to measures of parent and teacher perceptions of skills and behaviours.

Authors' conclusions

This review has little to offer in the way of implications for practice: there were only two studies, the numbers of participants included were small, and the two studies could not be compared directly to one another. In terms of research, randomised controlled trials involving large samples need to be carried out, involving both short and long-term outcome information and full economic evaluations. Research in this area is hampered by barriers to randomisation, such as availability of equivalent services.

SYNOPSIS

Children with autism spectrum disorder pose significant challenges within families. The involvement of parents in implementing intervention strategies designed to help their autistic children has a long history and is an approach used widely in current practice.

Findings of the review are based on only two studies of sufficient quality and are therefore limited. There is some evidence to suggest that parent training may provide benefits to both children and parents. However, large-scale randomised controlled trials are needed, to involve both short and long-term outcome information, to evaluate for which children parent-mediated early intervention may be most beneficial, and to include economic evaluations.

BACKGROUND

Definition:

Autism is the core disorder of the pervasive developmental disorders (PDD) as defined within the International Classification of Diseases and Related Health Problems, tenth edition (ICD-10) (WHO 1993) and the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (APA 1994), and is evident before the age of three years. Autism is, however, a dimension rather than a distinct category and generally understood as a spectrum, along which children experience varying degrees of difficulty in the areas of communication, social interaction, and a tendency toward repetitive behaviours and lack of imagination. Young children with an autism spectrum disorder may lack understanding of how to initiate and respond to joint attention with another person and have difficulties in social timing of communication. They also may not understand other people's intentions as expressed through language and gestures, even though they may appear affectionate and want to be with other people socially. They have difficulty with organising their responses, and with inhibition of repetitive behaviours and interests. For these reasons, children with autism spectrum disorder frequently pose considerable behavioural challenges to their parents and other family members.

Children with core autism have more profound difficulties, and are more likely to have associated learning difficulties, than those who have other diagnoses within the pervasive developmental disorders (e.g. Asperger's syndrome). In this review, the term 'autism spectrum disorder' will be used in preference to PDD, except where precision about ICD-10 categories is required (e.g. in reporting epidemiological data).

Prevalence

Prevalence surveys of children with core autism have generally agreed a best estimate of 5 per 10,000 (Fombonne 1999). However, the prevalence of PDD is considerably higher. Fombonne et al (Fombonne 2001) investigated the prevalence of pervasive developmental disorders in a nationwide survey of the mental health of British children aged 5 to 15. In this study the weighted prevalence of PDD was 26.1/10,000 (with a 95% confidence interval of 16.2 - 36.0/10,000). This represents more than one individual in 400, with a male to female ratio of 4.8:1. A prevalence of 26.1 per 10 000 children is consistent with the recent best estimates,

with some estimates being lower (e.g., Taylor 1999) at around 10 children per 10,000 and other estimates, particularly in surveys of young children with focused case-finding and diagnosis, much higher (e.g., Baird 2000 at 57.9 children per 10,000 and Chakrabarti 2001 at 62.6 children per 10,000).

The consistency of recent estimates toward much higher prevalence figures for the autism spectrum than those reported 30 years ago has drawn the attention of health professionals to a large group of children and their families who have important service needs. Children with autism spectrum disorder frequently pose considerable behavioural challenges to their parents and other family members which results in

high levels of parental stress (Koegel 2000). Recent increases in the awareness of autism spectrum disorders amongst general practitioners, health visitors and other health professionals have led to dramatic rises in the numbers of very young children being referred for assessment, diagnosis and support (e.g. Powell 2000).

Intervention:

Recent reviews have suggested positive outcomes for a number of early intervention programmes (Dawson 1997; Rogers 1998a; Smith 1999). However, the field of autism spectrum disorders is controversial, with a range of questionable claims for the efficacy of therapies and few successful replication studies (Harris 1998). Early intervention has taken a wide range of formats, some including parents as mediators, but not all. The child's diagnostic category has not always been specified clearly, but recent studies have included children with a range of severity within the autism spectrum. Programmes vary considerably in their theoretical background (Prizant 1998). Some approaches utilise applied behaviour analysis (ABA) in intensive programmes based at home, involving parents but delivered primarily by trained therapists (e.g. McEachin 1993a). This approach uses a 'discrete trial' training format for accurate control over children's learning. All aspects of development may be considered, and explicit generalisation strategies are incorporated. Other approaches have an educational framework, such as project TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren), with emphasis on structuring class environments through visual cueing, communication routines and individual tasks (e.g. Lord 1994). The TEACCH project aims to increase children's indepen-

dence and is designed to work on existing strengths that children may have rather than focussing on weaknesses. Finally, a number of programmes (eg. pivotal response training) emphasise the creation of naturalistic communication opportunities, enhancing motivation for social interaction and prompting specific social behaviours (e.g. Rogers 1991; Koegel 1995). Studies in this area of research have typically involved children aged between one and seven years (e.g., Smith 2000a, Koegel et al 1996, and Jocelyn 1998). Although programmes may differ in content they all advocate treatment implementation as early as possible as a matter of clinical urgency.

Recently reviewers have suggested that successful programmes have important similarities, whatever their apparently different theoretical foundations (e.g. Dawson et al 1997; Prizant 1998). Indeed, Rogers has conducted a comparative analysis of the elements of apparently contrasting programmes to demonstrate how each may address the underlying neuropsychological processing difficulties evidenced by children with autism, including intersubjectivity (interpersonal sharing including establishing joint attention to objects), emotional functioning and imitation (Rogers 1998b). Rogers suggests that programmes tend to be successful in early intervention for autism spectrum disorder if the agenda is intensive, involving a significant number of hours per week and if rigorous levels of structure and instruction are introduced into the child's world. Programmes may thus have to effect a change throughout the family in order to bring about positive changes in children's skills and behaviour.

Parents of children who have autistic spectrum disorder play an important role; they are critical components of the intervention process, without whom gains are unlikely to be maintained. The involvement of parents in implementing intervention strategies designed to help their autistic children has a history stretching back at least three decades (e.g. Schopler 1971). The potential benefits are increased skills and reduced stress for parents as well as children. Training parents in new skills has frequently been carried out in groups, allowing for mutual support. Increased parental skills allow for continual opportunities for learning in a range of situations. Training parents as 'therapists' allows intervention to begin early to involve consistent handling, and ensures that intervention is appropriate in enhancing children's earliest social relationships.

Within the autism intervention literature there are a number of individual studies which evaluate specific parent-mediated early intervention approaches in dealing with behaviour problems (e.g. Howlin 1987), in improving parent-child interactions (e.g., Dawson 1997; Koegel et al 1996), in facilitating communication (e.g. Prizant 1997), and in implementing a behaviour analytic approach (e.g. Smith 2000a). In addition, there are evaluations of the added value of parent involvement to a day-care or nursery programme (e.g. Jocelyn 1998). These studies need to be collated and summarised in a systematic way in order to evaluate the strength of ev-

idence concerning parent-mediated early intervention for young children who have autistic spectrum disorder.

Previous reviews of early intervention for autism spectrum disorder. The majority of previous reviews in this area (Dawson 1997, Harris 1998, Connor 1998, Green 1996, Gresham 1999, Probst 2001 and The National Research Council NRC 2001) have lacked a systematic approach, which minimises their comprehensiveness. With one exception (Smith 1999) reviews of early intervention for autism have not evaluated the methodological quality of the studies under discussion and have included investigations which lack scientific rigour and contain methodological weaknesses. Thus, conclusions have been drawn from evidence that may be biased.

Smith (Smith 1999) used a comprehensive search strategy to locate studies. He assessed the quality of those studies, but did not exclude on quality criteria. The review reported mainly on behaviour analytic approaches and did not focus explicitly on whether parents were involved in implementing intervention. It also had a very narrow basis of outcome comparison, reporting chiefly on intellectual functioning. Although a large proportion of children with autism have delays in intellectual functioning, dependence on intelligence tests as the sole comparison measure does not allow for the accurate evaluation of different intervention approaches. Measurement of key outcomes for a child with autism spectrum disorder should go further, to include measures of language, behaviour, and interaction with others. Secondary or collateral effects of parent training (e.g. family functioning and parental stress) should also be compared to give a full evaluation of different programmes. One review has been published which focuses on parent-mediated early intervention approaches to early intervention for autism (Probst 2001). However, this review was not carried out using a systematic approach and included studies of varying methodological quality, which limits the validity of its findings. Considering the importance of parent-implemented interventions for autistic spectrum disorder and the current rising trend in new programmes, a systematic review based on reliable evidence will provide much needed guidance for the clinical community and for parents of children who have autistic spectrum disorder.

OBJECTIVES

To determine the extent to which parent-mediated early intervention is effective in the treatment of children aged 1 year to 6 years 11 months with autistic spectrum disorder. In particular, to assess the efficacy of parent-mediated early intervention in enhancing autistic children's language, behaviour and social interaction, and in terms of secondary measures, such as parental confidence and parental stress.

CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW

Types of studies

Randomised controlled trials in which participants have been randomly allocated to an experimental and a control/comparison group.

Quasi-randomised controlled trials (where, for example participants have been allocated following a sequential assignment (such as alternate date of referral)).

A comparison group of children who receive no treatment, a waiting list group or comparison intervention.

Types of participants

Children aged 1 year to 6 years 11 months diagnosed with any of the following:

Autism

Asperger syndrome

Pervasive Developmental Disorder (PDD)

PDD Not Otherwise Specified (PDD, NOS)

A range of other disorders may be diagnosed as co-occurring with autism or PDD including attention deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder, developmental disorders of motor function and most commonly specific and general learning problems (Baird 2000).

Therefore, studies involving participants who have a dual diagnosis will be included. Studies utilising diagnostic criteria set out in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10) or their predecessors will be included if an Autism Spectrum Disorder or PDD was the primary diagnosis.

Types of intervention

Interventions with a significant focus (see earlier and previous comments/queries) on parents as the mediators. That is, the intervention is designed to train parents in interventions to improve the management of their child's autism related difficulties.

In a change to the previously published protocol, we have decided to include trials where a teacher/professional intervention takes place in partnership with the parents, provided that the emphasis is on parental input. The proportion of hours of input to the child should be presented as equivalent at most. The intervention should be replicable.

Training can be provided on a group or individual basis. Studies which include drug treatments, or treatments which aim to have physiological effects (e.g., dietary intervention), and surgical interventions, are excluded.

Types of outcome measures

Studies with objective (ie. standardised and/or previously validated), child related outcome measures were considered, e.g. assessment of specific child skills. These outcomes were measured in the intervention and comparison group, pre- and post- intervention. No direct child observation data were reported; where they are included in studies in future, they will be reported.

The primary outcomes that were searched for included: child language progress; child positive behavioural change; parent interaction style.

The secondary outcomes that were searched for included: parent confidence; reduction in levels of parental stress.

SEARCH STRATEGY FOR IDENTIFICATION OF STUDIES

See: Developmental, Psychosocial and Learning Problems Group search strategy

Published and unpublished trials were considered, with no language restrictions.

Search strategy design:

[(child or child synonyms) and (autism or autism synonyms) and (parent or parent synonyms) and (intervention or intervention synonyms)]

Subject search:

1 (child* or infant* or babies or baby or toddler* or girl* or boy* or pre-school* or preschool*)

2 (autis* or pervasive developmental disorder or PDD or language delay* or communicat* or speech disorder* or childhood schizophrenia or Kanner* or Asperg*)

3 (parent* or caregiver* or care-giver* or family or families or mother* or father* or maternal* or paternal*)

4 (treat* or therap* or intervent* or program* or train* or rehabilit*)

5 (#1 and #2 and #3 and #4)

In all searches appropriate truncations and possible misspellings were included and the search terms were adapted for different databases. Other sources of information were examined including the bibliographies of systematic and non-systematic reviews and reference lists of key articles identified through the search strategy. Experts in the field were contacted e-mail in order to identify unpublished studies. Key journals (Journal of Autism and Developmental Disorders and the Journal of Child Psychology and Psychiatry and Allied Disciplines) were hand searched to identify studies that were not electronically catalogued in the databases searched.

The following data bases were searched:

ERIC (Educational Resources Information Centre - 1966 to present day)
The Cochrane Controlled Trials Register (Cochrane Library 2002, Issue 1)
MEDLINE (1966 to present day)
EMBASE (Excerpta Medica - 1980 to 2002)
PsycINFO (Psychological Abstracts - 1887 to 2002)
CINAHL (Cumulative Index to Nursing and Allied Health Literature - 1982 to 2002)
Dissertation Abstracts International (1861 to 2002)
Social Sciences Abstracts (1980 to 2002)
Sociological Abstracts (1963 to 2002)
Linguistics and Language Behavior Abstracts (1973 to 2002)
National Research Register (NRR - Issue 1, 2002)
LILACS (Latin American and Caribbean Health Sciences Literature - 1982 to 2002)

METHODS OF THE REVIEW

Selection of studies:

All citations generated through the search strategy were transferred to a reference management programme (EndNote). Initial screening of titles and abstracts from the search (TD) identified potential studies for inclusion. Studies that differed greatly from the inclusion criteria were excluded (e.g. prevalence studies), whereas those studies that appeared to be appropriate were kept, that is, they appeared to be about intervention with children with an autism spectrum disorder, and there was some mention of parents' role. Two reviewers (TD and HM) independently assessed and selected studies for inclusion from the pool of remaining studies. No disagreements over inclusion occurred.

Assessment of methodological quality:

Two reviewers (TD and HM) carried out appraisal of the included studies. The reviewers allocated studies to categories on the basis of concealment of treatment allocation as per the Cochrane Collaboration Handbook (Clarke 2001). That is, the reviewers analysed the description of how children were allocated to one treatment arm or another in terms of how independent the process was from influence by the treatment providers or by the parents. The Cochrane Collaboration Handbook criteria are based on the evidence of a strong relationship between the potential for bias in the results and the allocation concealment defined by the following:

A - Low risk of bias (adequate allocation concealment, such as centralised allocation, sequentially numbered sealed opaque envelopes, etc)

B - Moderate risk of bias (questionable allocation concealment; appears to follow adequate procedure but not fully specified)

C - High risk of bias (inadequate allocation concealment, such as alternate allocation, allocation by days of the week, open list of numbers)

For the purpose of quantitative analysis studies were included only if they meet criterion A or B, that is that they had low or moderate risk of bias; any studies with a high risk of bias were excluded. All included studies were further critically appraised according to the following criteria:

- Was the assignment to treatment condition truly random
- How complete was the follow-up; were study drop-outs accounted for?
- Where study attrition did occur was an intention-to-treat analysis carried out?
- Were those assessing outcomes blind to the treatment allocation?

The characteristics of included studies are reported in the included studies table.

The inclusion of multiple baseline studies was considered but rejected. The available studies are all of short duration, with baselines compared usually across participants or across tasks. The review aims to evaluate not simply whether a parent or a child can master a particular technique or behaviour, but whether a parent-mediated approach to intervention is of benefit. The difficulties of interpretation of results for individuals leads to the likelihood of positive publication bias.

Data management:

Citations were stored and organised using EndNote reference manager software. Two authors (TD and HM) extracted data independently using a data-extraction form developed for this purpose. Data extracted included: study location, methods, participant details (diagnostic description and severity), type of intervention (including the intensity and duration of intervention) and outcomes.

Data Analysis:

Due to excessive levels of heterogeneity between study interventions and outcomes it was not possible compare the data from the two included studies directly in the form of a meta-analysis.

Missing Data:

Missing data and dropouts were assessed for each included study. We report number of participants who were included in the final analysis as a proportion of all participants in each study.

Measures of Treatment Effect:

Categorical data: No dichotomous outcomes were reported. In future, if outcomes from either standardised instruments or diagnostic risk evaluations (ie. cut-off points) are expressed as proportions, a standard estimation of the risk ratio and its 95 percent confidence interval will be calculated.

Continuous data:

Continuous data were analysed on the basis that the means and standard deviations were available and that there was no clear evidence of skew in the distribution.

Qualitative data:

No qualitative data will be considered in the review.

Assessment of Heterogeneity:

Excessive heterogeneity was apparent between the included studies in terms of the type of intervention and comparison groups used and the outcomes measures. We were therefore unable to make direct comparisons.

Data synthesis:

Data synthesis was performed using RevMan 4.1 (Update Software).

Impact of Study Quality:

Only a limited number of studies were eligible for inclusion as randomised study designs with comprehensive concealment have been infrequently carried out in this area of research, for reasons discussed later (ie. in Implications for research). In future, impact of study quality will be determined by separate analyses of randomised and quasi-randomised studies.

Publication bias:

The possibility that study selection was affected by a publication bias was not assessed in this first version of the review, as too few studies were available. In future, should further studies become available, we will investigate publication bias by means of a funnel plot.

Sensitivity analyses:

Sensitivity analyses were not carried out, as it was not appropriate to undertake meta-analyses. In future, if studies are sufficient in number, sensitivity analyses will be undertaken, for example, in relation to the certainty to which the studies meet the inclusion criteria.

DESCRIPTION OF STUDIES

The search strategy located over 15000 articles; there were many duplications in this number, and many irrelevant articles located through using a wide search strategy. All databases yielded relevant citations, but the majority originated from PsychInfo, ERIC and Medline. From the initial yield of citations, 68 articles qualified for further inspection based on the abstract and were formally reviewed. The lead authors from the 68 studies were contacted to find out if they were aware of any published or unpublished studies that had not been identified through the database searches. Sixty-one authors were approached (via e-mail), which elicited 18 responses. One study was added to the list for formal review (McClannahan 1982), and one ongoing study was recorded (Elder 1998). Of the 68 studies five were published in a language other

than English including two from Italy (Micheli 1999 and Panerai 2000), two from Japan (Ikeda 1974 and Ono 1994), and one from Turkey (Sucuoglu 1994). These studies were translated to a degree necessary to understand the essentials of the study. Nine were unpublished doctoral dissertations (Battaglini 1995, Cafiero 1996, Celiberti 1994, Hungenmann 2001, Lee 1992, Mayo 1997, Shadduck 1990, Sirbasku-Cohen 2001, Thorwarth 1982), and one was an unpublished conference paper (Chambliss 1994). 66 of the 68 studies obtained in full for formal review were excluded from the systematic review (see excluded studies table), primarily on methodological grounds (N = 55). Few studies involved a properly constituted concurrent control group, and of those that did, only five used random allocation. Some studies were excluded on the basis that the participants did not have a diagnosis of autism spectrum disorder (N = 8), or the intervention did not include or focus on parent-mediated early intervention (N = 1). Of the four studies with random allocation of participants, two used no child related outcome measures, leaving two studies which met the inclusion criteria for this review.

Jocelyn 1998 carried out a randomised controlled study comparing parent training (Autism Preschool Program, APP) and community day care to community day care (standard services) alone. In APP 16 parents were trained for 15 hours over a 10 week period in functional analysis, empathy skills and problem behaviour training. In addition each family participated in three case conferences concerning problems and potential solutions and two home visits were made by the programme social worker. Their children attended a day care centre for an average of 21.4 hours per week over 12 weeks. The childcare workers in each day care centre attended the same 15 hours of educational seminars as the parents and had additional coaching in developing goals and treatment approaches. The expectations placed on parents for active intervention with their child are not made clear in the paper. However, given that the children spent what may be interpreted as an average of 4 hours per day in day care, it was considered that the parents had the majority responsibility for implementing the strategies taught, and thus that the study met inclusion criteria. In the standard service group the autistic children from 19 families received day care for an average of four hours per day for twelve weeks plus social worker support. Child outcome measures included the Autism Behaviour Checklist (Krug et al 1980) (independent assessor and parent) and the Early intervention/preschool developmental profile (Schafer 1981). Parental outcome measures included the Stress-Arousal Checklist (Mackay 1978), the Family Assessment Measure (Skinner 1983) and the TRE-ADD Autism Quiz (Factor 1987). In addition to participating Mothers and Fathers, the TRE-ADD Autism Quiz was also administered to the childcare workers. Smith 2000a carried out a randomised controlled study to compare Intensive Treatment to Parent Training. In this study 28 families participated, with 15 in the Intensive Treatment group and 13 in the Parent Training group. The intensive treatment was based on Lovaas' (Lovaas 1981) treatment manual. Children re-

ceived 30 hours intervention per week for 2 to 3 years delivered by 4 to 6 student therapists working under close supervision. This treatment was based, at least for the first 18 months, on discrete trial learning procedures at home. The goal of intensive treatment was to “maximise children’s intellectual, adaptive and socioemotional functioning”. At approximately one year (with large variation across children), the children were entered into classrooms in the public schools for typically developing children. If children did not master the appropriate skills necessary for a normal school environment within 18 months, they were enrolled in special education classrooms based on an individualised educational plan. In the Parent Training group parents were taught the treatment method from Lovaas’ (Lovaas 1981) treatment manual. Parents received two sessions per week totalling five hours, for three to nine months. Parents were asked to implement training with their child for a further 5 hours per week. Parents also received three-monthly consultations with the project director. Children spent 10-15 hours in special education classes for the duration of the parent training. (NB an erratum notice appeared concerning the original publication of this paper in the *American Journal of Mental Retardation*, 105 (6), 508, correcting an error on page 278 of the original article and involved school placements. Clarification was given that two children in the intensive treatment group and four in the parent training group were in regular education classes with support.

Child outcome measures used by Smith et al included IQ (Stanford-Binet Intelligence Scale (Thorndike 1986) (if they did not achieve basal levels then the examiners administered the Bayley Scales of Infant Development-Mental Development Index (Bayley 1969)), the Merrill-Palmer Scale of Mental Tests (Stutsman 1948), Reynell Developmental Language Scales (Reynell 1990), the Vineland Adaptive Behavior Scales (Sparrow 1984), the Achenbach Child Behavior Checklist (Achenbach 1991), and a parent composite rating of child progress, work load and stress (non-standardised measures). Parental outcome measures included parental stress related to the programme, parental rating of workload and parental rating of treatment quality (The Family Satisfaction Questionnaire, Smith 1990, non-standardised measures).

METHODOLOGICAL QUALITY

TREATMENT ALLOCATION

The included studies were randomised controlled studies. Jocelyn 1998 stratified their randomisation according to severity of diagnosis using the Childhood Autism Rating Scale (CARS, Schopler 1986). A sealed opaque envelope method of allocation concealment used was by Jocelyn 1998, operated by an independent research assistant. Smith 2000a used a matched pair random allocation according to diagnosis (autism or PDD) and I.Q. (Bayley Scales of Infant Development-Mental Development Index, Bayley 1969). An independent statistician used a random numbers table

to generate treatment allocation; this method of concealment was satisfactory and at low risk of bias.

ATTRITION

Smith et al do not report that any study dropouts occurred during their studies (Smith 2000a). Jocelyn et al reported one participant drop out from the parent-training group (Jocelyn 1998). This participant’s condition and his parents’ reasons for withdrawing him from the study were specified. No analysis was carried out in the Jocelyn et al study based on treatment allocation (intention-to-treat analysis).

BLINDING TO TREATMENT

In studies in which both the treatment facilitators and the parents are integrally involved with the mechanics of the intervention, such as parenting programmes, it is not possible to blind either facilitators or parents to the type of treatment being implemented or received.

ASSESSMENT OF OUTCOMES

One method of minimising bias is to blind the assessors of clinical outcomes at every stage of assessment. Both studies used clinicians that were independent from the study to make a diagnosis pre-randomisation (Jocelyn 1998, Smith 2000a). They also made use of blind assessors to carry out assessments post randomisation, which increases the validity of these studies’ results. Given the nature of the designs and interventions used in these studies, with both the treatment facilitators and the parents integrally involved with the mechanics of the intervention, the researchers used the maximum level of blindness available during the active phases of these studies. A further measure that could have been taken to ensure that the results were valid would have been to carry out blind analysis of the results using an independent statistician, but none of the studies reported having carried out this procedure.

DISTRIBUTION OF CONFOUNDERS

Sample size

Samples need to be of sufficient size for differences between groups to achieve a statistically significant change. Small participant samples can obscure treatment effects and result in an unequal distribution of confounders. The required sample size can be obtained using power calculations. Neither of the included studies reported such a calculation. Included studies had limited sample sizes (Jocelyn 1998 N = 35, Smith 2000a N = 28). Such small sample sizes may have seriously affected the reliability of the results. It should be noted, however, that within the research field of autism such numbers are above those usually included in studies. Further to the problem of sample size, some commentators may consider that methods of matching (Smith 2000a) have the potential to reduce the reliability of the results by entering systematic bias into the analysis whilst attempting to control for severity or I.Q.

Characterisation of sample

Both studies reported some information concerning sample demographics (e.g. age, gender, ethnicity, household income, etc),

but very little about recruitment, thus rendering very difficult for judgment to be made about the representativeness of samples.

ASSESSMENT SCHEDULE

Jocelyn 1998 used a pre-post measurement with a twelve-week intervention period. This measurement regime assessed only the change immediately following the intervention, and did not measure any possible process changes that may have occurred during treatment, nor did it assess changes in the long-term. Smith et al did account for changes in the long-term by reporting an average 4 year 10 month follow-up. However, they did not make any assessments during the time between pre-intervention and an average of two years following the end of intervention follow-up after the start of intervention, during which time any intervention effect could have been obscured by a multitude of intervening events. Although randomisation controls for the distribution of intervening events, where the time interval is great it no longer becomes possible to attribute effect to the intervention unambiguously. A long follow-up period between the termination of therapy and follow-up also casts doubt on the memory requirement for parents rating aspects such as stress related to the treatment programme. The lengthy duration of this study also raises questions concerning levels of participant compliance and initial selection. There were no participant dropouts from this study and it is fair to say that levels of participant compliance in regard to this type of intervention are usually high. However, none of the included studies reported data concerning participant compliance.

PUBLICATION BIAS

With the inclusion of only two studies, it is very difficult to assess the possibility of publication bias. It is impossible to carry out any meaningful analysis of publication bias based on two studies that involved differing comparisons.

OVERALL ASSESSMENT

Based on these factors both included studies were classified, in terms of risk of bias, or internal validity, as having a moderate risk of bias.

RESULTS

It is important to voice a cautionary note in respect to these results. Although the included studies were found to have reasonable methodological integrity with only a moderate risk of bias, there are only two of them, and they do not contain a large number of participants. The two studies are not directly comparable, as the intervention and outcome measures used in these studies are very different, further reducing the overall interpretability of the results.

The following section provides the results from the included studies where study means and standard deviations were available. Where it has been possible to calculate the difference in means (DiMs) and 95% confidence intervals, these have been reported.

Where DiMs and 95% confidence intervals have been calculated and reported, a minus sign indicates that the results favour the parent-training group. Psychological interventions tend to be measured in a positive way, for instance, language improvement, rather than a decrease in stress. A mixture of signs (+ or -) only adds confusion; therefore the signs were inverted in some cases to aggregate the results. For the results of the Parent Training versus Intensive Treatment (Smith et al 2000), the post-intervention scores have been used to calculate effect sizes rather than the change scores as these were not available. This gives a comparison of the post intervention difference between the groups. It should be noted that in the parent training and day care versus day care alone, change scores were available and have been used to calculate the DiMs and confidence intervals. Thus, results from parent training and day care versus day care alone (Jocelyn 1998) reflect a comparison between the amounts of change that occurred within the groups, a comparison that takes a degree of individual difference into account.

All of the results for each study are reported except where measures were constructed in a way in which it was impossible to carry out numerical analysis. Significant positive change occurred in the Day Care alone group concerning general knowledge of autism and the amount of assistance that they received in regard to their child on a day-to-day basis. Results for all other measures are as follows (please see Additional Tables 01 to 04):

CHILD OUTCOMES

1.1. Jocelyn 1998. Parent Training plus Day Care versus Day Care alone. A statistically significant difference ($p = 0.01$) was found between the two groups on the language component of the Early intervention/Preschool Developmental Profile, although it is difficult to tell from the DiM -4.2 [CI $-7.41, -0.99$] whether this improvement signifies clinical importance. Measures that favoured the Parent Training group but did not reach statistical significance were the independent assessor rating of the child using the Autism Behaviour Checklist (Krug et al 1980) and the cognitive component of the Early intervention/Preschool Developmental Profile (Schafer 1981). Measures that favoured the Community Day Care control group, but did not reach statistical significance were the parental assessment of the child using the Autism Behaviour Checklist (Krug et al 1980), and the perceptual/fine motor, social emotional, self-care, and gross motor components of the Early intervention/Preschool Developmental Profile (Schafer 1981).

1.2. Smith 2000a. Parent Training versus Intensive Treatment. Overall, the child related outcomes for Parent Training versus Intensive Treatment favoured the Intensive Treatment group. The Intensive Treatment group achieved statistically significant results relating to higher I.Q. (Stanford-Binet Intelligence Scale, Thorndike 1986, or Bayley Scales of Infant Development-Mental Development Index, Bayley 1969) ($p = 0.04$) with a DiM of 16.82 [CI $0.58, 33.06$] signifying an improvement of one standard deviation. Children in the Intensive Treatment group improved sig-

nificantly on the Merrill-Palmer Scale of Mental Tests (Stutsman 1948) ($p = 0.04$) with a DiM of 15.16 [CI 0.14, 30.18], again this is an improvement of one standard deviation. These findings concerning I.Q. have clinical importance, although the confidence intervals relating to these results are wide, inferring a degree of uncertainty concerning the precision of these findings. Results also favoured the Intensive Treatment group on the Reynell Developmental Language Scales (Reynell 1990) total measure. One child-related outcome measure mildly favoured the Parent Training group; the parental rating of child workload and child stress during treatment (but parent's own stress was rated higher for the Parent Training group). These positive outcomes in favour of Intensive Treatment applied to direct testing of child skill levels. Of the measures that relied on report by parents and teachers, none showed a statistically significant difference between the groups on child outcomes nor produced a clinically significant change (i.e. Vineland Adaptive Behavior Scales, Sparrow 1984, parent; Child Behavior Checklist, Achenbach 1991, parent and teacher).

PARENTAL OUTCOMES

2.1. Jocelyn 1998. Parent Training plus Day Care versus Day Care alone. Both mothers and childcare workers in the Parent Training group made a statistically significant gain in their level of knowledge concerning autism, according to results of the TRE-ADD Autism Quiz (Factor 1987). A DiM of -1.70 [CI -3.2, -0.19] was found for mothers ($p = 0.03$) and a significance level of $p = 0.008$ and a DiM of -2.70 [CI -4.70, -0.70] was found for the childcare workers ($p = 0.008$). It is difficult to infer clinical significance from these DiMs concerning this little known autism quiz. None of the other parental outcome measures reached a level of statistical significance. On the whole, more measures reported favourable outcomes for the Parent Training group including, both maternal and paternal measures of stress and measures of maternal arousal (Stress-Arousal Checklist, Mackay 1978) and maternal outcomes using the Family Assessment Measure. Results that favoured the Day Care group were paternal self-ratings of arousal (Stress-Arousal Checklist, Mackay 1978), and paternal outcomes concerning the Family Assessment Measure (Skinner 1983).

2.2. Smith 2000a. Parent Training versus Intensive Treatment. Two outcomes significantly favoured the Intensive Treatment group in terms of Parental results. Using a non-standardised measure, parental stress during treatment was rated to be significantly less in the Intensive Treatment group ($p = 0.008$) than in the Parent Training group. Parental stress was measured on a 7-point Likert scale, with a DiM of 1.52 [CI 0.40, 2.64] this infers only a moderate level of clinical significance. Using a non-standardised measure, parent rating of workload during treatment was rated to be significantly less in the Intensive Treatment group ($p = 0.005$). Parent ratings of child workload were measured using a 7 point Likert scale and with a DiM of 1.09 [CI 0.47, 1.71]) it is difficult to attribute any clinical significance to this finding. Using a non-standardised measure, parental rating of treatment quality was also seen to slightly favour the Intensive Treatment group.

The only measure not to be reported is the Client Satisfaction Questionnaire (a non-standardised measure) reported by Jocelyn 1998. This measure asked the participating parents four questions concerning their satisfaction with the intervention; answers were recorded on a five point Likert scale, with the mean, median and p value reported.

DISCUSSION

The results of this review must be viewed with a great deal of caution. Only two studies with small sample sizes were identified for inclusion. The studies also differed in five important ways. Firstly, they differed in terms of their theoretical approach, although both included studies utilised an intervention based broadly on behavioural principles. Secondly, the studies differed in the intensity of parent-mediated early intervention, and it may be the case that there is a 'dose dependent' effect involved in parent-mediated early intervention for autism. Thirdly, there were vast differences in the duration of the parent-mediated early interventions delivered; a long-term intervention may be more effective than a short one regardless of the relative intensity. Fourthly, there were differences in context, i.e. what the parent-mediated early intervention was coupled with. Parent-mediated early intervention should not be regarded as a stand-alone treatment for autism, but as a useful adjunct within a complex treatment package. Finally, and what makes direct comparison between studies most difficult, was the type of intervention comparison. One study compared parent mediated early intervention with higher-cost, more intensive intervention delivered predominantly by professional workers. The other evaluated a combined training intervention for parents and child care workers, and so their relative impact on children could not be separated in the outcome measures. Thus, fundamentally the design of neither of the studies is fully satisfactory in allowing the review to focus on the core objective of determining the extent to which parent mediated early intervention is effective.

When parent-mediated early intervention and community day care were compared to community day care alone (Jocelyn 1998), it was found that it had a significant effect on child language progress. It is not possible to be certain from these results why the intervention should have had a significant positive effect on the children's language. It may be the case that with an increased understanding of the children, the parents (and the childcare workers) modulate their behaviour to make communication easier and allow the children to display and practice their linguistic competence. A further mechanism might be change in adults' behaviour consistent with, and positively reinforced by, the training programme; however, for this to produce measured progress in a few weeks in children's use of language is perhaps less plausible. From the design of the study, it is not possible to determine the extent to which the impact on children can be attributed to changes in the parents, or changes in the care workers, or perhaps both in

conjunction, even though the children spent much longer hours in the care of parents than in day care. However, it seems that there was a measurable impact of the course on the adults. Both mothers and childcare workers in the intervention group improved significantly in their knowledge as measured by the TRE-ADD Autism Quiz (Factor 1987).

Smith et al measured outcome for children in two main ways, ability (through standardised tests of I.Q. and non-verbal cognitive ability) and everyday living skills and behaviour (through parent and teacher report). Significant change was found on the two ability measures in favour of the intensive treatment group. However, it is not clear from the paper, but is very likely given the mean follow-up time of 4 years and 10 months, that different I.Q. tests were used on each occasion. This calls into question the size of the real change (Magiati 2001). The Merrill-Palmer is a standardised assessment of cognitive ability with emphasis on visuo-spatial skills and has been used in a number of studies because of its acceptability to young children with autism. However, it has not been revised since 1948 (Stutsman 1948) and the framework for measurement and the out of date norms may have unknown biasing effects on the data. It is also possible to postulate that the main effect of the intensive treatment was to facilitate child compliance to adult direction, so that children became better at doing the tests, rather than truly advancing in generalisable cognitive skills. The conceptual framework for ability testing (such as I.Q.) is that it should capture a relatively unchanging quality in the child, and therefore observed change may result from other factors, such as test compliance. Those involved in this study who knew the children best (the children's parents and teachers) did not score the long-term effects of the Intensive Treatment any higher than the effects of Parent Training in terms of children's everyday living skills and co-operative behaviour. This study reported that parents' rating of their stress and workload during treatment was significantly lower in the intensive treatment group. However, these ratings were made some years after active treatment ceased, casting some doubt on their validity. Therefore, both of the included studies raise many more questions than they answer.

Summary

Overall, the only results found significantly to favour parent-mediated early intervention in this review were that short-term language improvements were greater for those children receiving parent-mediated early intervention than for those from community day care alone (Jocelyn 1998), and that mothers and child care workers who received parent training gained knowledge concerning autism. It could also be said that parent-mediated behaviourally oriented early intervention is slightly more effective than community day care alone, but not as effective as intensive home-based treatment, mostly delivered by professionals (Lovaas 1981). But this might be attributable to the difference in the amount of intervention that the Intensive Treatment group received compared to the Parent Training group. It might also be the case that in the Jo-

celyn et al study there was not an adequate amount of time before measurement for the effects of parent-mediated early intervention to become apparent in children's social and communicative functioning (Jocelyn 1998). It could be that parent training must first be internalised by the parent; it will then take time for the parent to begin to operate on this training, for training to generalise to different settings (Cordisco 1988) and still more time for it to have an effect on the child. A further question must be raised concerning the length of follow-up in the Smith 2000a study. Four years and ten months is a long time, certainly enough time for the processes of parent-mediated early intervention to have taken hold, but also long enough for intervening events to occur, such as contrasts in educational input. Had Smith et al made regular follow-up measures of potential confounders, such as life events and education, the results of this study might have been more interpretable.

Indeed any conclusion regarding whether or not the active involvement of parents in delivering early intervention to their young children with autism gives added value cannot be based on the evidence from these two studies. There is a body of less reliable evidence from studies that involve a concurrent (non-randomised) control group (not included in this review) which indicates positive findings in some areas in favour of parent-mediated early intervention. From thirteen studies, five suggested improvements in child outcomes (Birnbauer 1993, Goodman 1984, Howlin 1981, Ozonoff 1998, Sherman et al 1988), five found improvements in parental outcomes (Brightman 1982, Bristol 1993, Koegel et al 1996, Shaddock 1990, Schreibman 1991), two indicate improvements in child and parental outcomes (Harris 1982 and Neef 1995), and only one study suggested no effect of parent training (Celiberti 1994). The existence of such research is encouraging, although it should be noted that the research designs used in these studies are subject to an excessive level of potential bias. In time, as methods of randomisation become more widespread in the field of autism research perhaps, a more satisfactory assessment of the impact of parent-mediated early intervention will be possible.

AUTHORS' CONCLUSIONS

Implications for practice

This first review has little to offer in the way of implications for practice. The principle of involving parents and increasing relevant skills, allowing generalisation of programmes for children within the home, and supporting parents' confidence, is self-evident, though potential disadvantages are not well explored. The research currently available does not allow conclusions to be drawn about best practice. The comprehensive programmes for children which are best known (see The National Research Council Report, NRC 2001) all incorporate training of parents, but no research is available comparing different ways of helping parents to master

skills. Short-term training courses, often added-on to a child's educational placement, are unlikely to be sufficient to ensure parents can develop long-term ability to solve newly arising problems. It is a matter of urgency for good quality evidence to be available to parents and to commissioners and providers of services to guide service development.

Implications for research

The implications for research are numerous. Current research in progress in the UK concerning early intervention for autism spectrum disorder is beginning to reach a level where randomised methods are appropriate (Charman 2002). Important preliminary studies have been carried out to investigate whether parent mediated early intervention can work for children with autism spectrum disorder (e.g Bibby 2001, Holmes 1982, Howlin 1987, and Mudford 2001) with some encouraging outcomes. Research designs that have less rigour than RCTs (e.g. multiple baseline designs and controlled studies) may initially be used to provide a rich data source concerning the variety in individual responses and the mechanics of the intervention process. Well-designed single case studies are particularly appropriate where there is individual target setting, and/or where the magnitude of observed changes in parents and in children can be related to well-established relevant measures; however, for research evidence at the level required to guide broad strategies for service development, large randomised controlled trials are required. However, there are barriers within the field of autism research that must be overcome before this need can be met. The key research problems relate to equipoise (the ability to offer a choice between two alternatives of which no hard beliefs are held concerning their relative effectiveness by clinicians or participants) and sample size.

Equipoise

There are a number of psychological, educational and physical interventions available for the treatment of autism spectrum disorder based on different theoretical backgrounds (Prizant 1998). Each of these interventions has made various claims concerning effectiveness. This information is freely available through various media including the Internet. Parents of children who have a diagnosis of autism spectrum disorder frequently carry out their own searching and form their own views concerning the effectiveness of interventions. It is therefore very difficult to propose an RCT study to potential participants who have already made up their minds concerning the effectiveness of the interventions offered, and this affects equipoise. Problems of equipoise have the potential to affect all RCTs; potential participants are rarely pleased with the idea that their treatment is decided on a random basis. However, this problem is particularly ubiquitous in autism treatment research. The pressure to treat a child early is great, and the number of treatments that claim to be effective, indeed to offer 'cure' for a developmental disability, is greater than in many other areas of research.

Problems concerning equipoise therefore have a great implication for research. Research must be designed in such a way that enables methodological rigour, in the form of an RCT, but allows a workable level of equipoise. This will involve a high degree of ingenuity on the part of researchers who must design meaningful studies of comparable interventions that are acceptable to participants. In an environment where personal resources are crucial, the inducement of providing an intervention service free of charge within a research setting must be a valuable tool for recruitment.

However, this poses major difficulties for adequate funding. It may also be the case that certain types of randomised designs prove to be more appropriate than others within this field. Both cross over and waiting-list control designs ensure that every participant involved in a study receives the intervention, although such designs may provide problems of interference when long periods of follow-up are used. The idea of stacked odds in favour of the 'active intervention' (stratified sampling), may also prove an attractive option to parents. However, evidence suggests that parents who receive no intervention within a research design, or receive an intervention with which they are dissatisfied will quickly resort to other forms of help (Charman 2002).

Sample size

Problems concerning relatively low sample sizes are potentially easier to solve. The reason that sample sizes in autism research tend to be so small is due to the relative rarity of the disorder (in terms of rate of likely early recruitment to a research intervention in a limited geographical area) and some difficulties in early diagnostic certainty for both professionals and parents (Fombonne 2001). Without a substantial increase in the level of resources available to research groups, and a degree of cooperation between groups nationally, and potentially internationally, the numbers of participants involved in early intervention autism research will remain small and continue to lack the power necessary to provide reliable evidence for this important area of research.

In conclusion, there is an increasing need for randomised controlled trials involving large populations to be carried out. Studies need to involve both short and long-term outcome information in order to evaluate for which parents and children parent training may be most beneficial. Importantly, full economic evaluations need to be carried out in parallel with randomised controlled trials to evaluate the cost-effectiveness of various approaches to intervention, including alternative models of parent involvement.

POTENTIAL CONFLICT OF INTEREST

None known.

ACKNOWLEDGEMENTS

We would like to thank all the members of the Cochrane Developmental, Psychosocial and Learning Problems Review Group editorial team, with special thanks to Geraldine Macdonald and Jane Dennis for the provision of ongoing guidance and support, and Jo Abbott for her assistance with database searching. We would also like to thank the Nuffield Foundation for the financial support of the review.

SOURCES OF SUPPORT

External sources of support

- The Nuffield Foundation UK

Internal sources of support

- No sources of support supplied

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*Indicates the major publication for the study

T A B L E S**Characteristics of included studies**

Study	Jocelyn 1998
Methods	Parents were randomly allocated, using the sealed envelope, method to receive either Autism Preschool Program (APP) and community day care or Community day care alone. Randomisation was stratified according to the severity of the child's autistic symptoms according to their Child Autistic Rating Scale (CARS) score. All assessments were made by professionals blind to the participants treatment. Pre and post measures were used.
Participants	Participants were all referrals to a child development clinic. 36 children and their parents were randomized. Children were aged between 24 and 72 months. All participants had a DSM III (R) diagnosis of autism.
Interventions	Autism preschool program (APP) (n = 16). Parents were trained for 15 hours during 12 weeks in functional analysis, empathy skills and problem behaviour training, as well and two home visits. Their children attended a day care centre during this time. Community Day Care (standard services) (n = 19). Children received 15 hours of day care during twelve weeks plus social worker support.
Outcomes	Child outcomes; Autism Behaviour Checklist (independent assessor and parental), Early intervention/preschool developmental profile (cognition, language, social/emotional, self-care, gross motor, perceptual/fine motor). Parental outcomes; Stress Arousal Checklist, Family Assessment Measure, and the TRE-ADD Autism Quiz.
Notes	
Allocation concealment	A

Study	Smith 2000a
Methods	Random matched pair allocation based on their diagnosis (autism or PDD) and their I.Q. (Bayley) using a random numbers table. Participants were assigned to either Intensive treatment or Parent training. All assessments and measures were performed by independent, blind professionals. A three month pre treatment measure, and a mean follow-up of 4 years and 10 months was used.
Participants	Participants were referred to the UCLA young autism project between 1989 and 1992. 28 children and their parents participated. Children were aged between 18 and 24 months, within a one hour drive of the research centre, had an IQ score between 35 and 75 points, and had no major medical problems.
Interventions	Intensive treatment (n = 15). This intervention was based on Lovaas' (1981) treatment manual. Children received 30 hours intervention per week for 2 to 3 years. This treatment was based, at least for the first 18 months, on discrete trial procedures. After this time, they attended a school with an aid, or special education classes

Characteristics of included studies (Continued)

	Parent training (n = 13). Parents were taught the treatment method from Lovaas' (1981) treatment manual. Parents received two sessions per week totalling 5 hours for three to nine months. Parents also received three-monthly consultation with the lead author. Children spent 10-15 hours in special education classes for the duration parent training.
Outcomes	Child outcomes; IQ, (Bayley or Stanford-Binet) Merrill-Palmer, Reynell Comprehension/Expressive/Comprehension + Expressive, Vineland Adaptive Behavior Scale, Child Behaviour Checklist parent/teacher rating, Parent composite rating child progress/work load/stress. Parental outcomes; parental stress, parental rating of treatment quality and parent rating of workload.
Notes	
Allocation concealment	A

Characteristics of excluded studies

Anderson 1987	No control group. 14 children and families participated in the May Institute parent-training program. Improvements in parental knowledge and behavioural techniques. Significant improvements in child measures of mental age, social skills and language.
Anderson 1989	No control group. 14 children and families participated in the May Institute parent-training program. Improvements in parental knowledge and behavioural techniques. Significant improvements in child measures of mental age, social skills and language.
Battaglini 1995	No control group. 76 families involved in parent training. Voluntary information received suggested that parental stress was the strongest contributor to study attrition.
Bernard-Opitz 1992	Descriptive study, no control group. 32 parents participated in an 8-hour training course. Parents considered the course useful.
Bibby 2001	No control group. 66 children. Improvements were found, but the interventions did not reproduce clinic-based results.
Birnbrauer 1993	Non-random treatment allocation. 9 experimental (The Murdoch Early Intervention Program), 5 control (no treatment). Children in the experimental group made some improvements.
Brightman 1982	Non-random allocation, only 9% of sample were diagnosed as being within the autism spectrum (n66) no raw data was presented, no sub-analysis was carried out concerning the ASD participants. 66 families were assigned to group parent training, individual parent training, or no treatment control. Trained parents showed improvements, but their children did not. Outcomes were similar for individual and group formats.
Bristol 1993	Non-random treatment allocation. 28 depressed mothers, 14 received TEACCH, 14 received no treatment. Mothers in experimental group became less depressed over time.
Cafiero 1996	This was a descriptive study with no control group. Four families received instruction in picture communication symbols, which helped to increase levels of communication.
Celiberti 1994	Child participants aged over 7 years. Nine children randomised to three groups, parent training, self-directed training with telephone consultations, self-directed training only. Few differences in outcome across the three groups.
Chambliss 1994	No control group. 5 families participated. Investigated parental factors associated with ABA treatment outcome.
Cordisco 1988	No control group. Three families participated in a multi-component training programme. Some generalisation of training procedures occurred.
Dawson 1990	No control group. 15 children and their mothers participated in facilitated play. Eye contact was increased.
Eiserman 1995	Participants did not have a diagnosis of autism spectrum disorder. 40 children with moderate speech and language problems were assigned to parent training or clinic based intervention. Few differences were found between groups at follow up.

Characteristics of excluded studies (Continued)

Elder 1995	No control group. Four families involved in parent training. Parental awareness of the child's needs were increased.
Freia 1999	No control group, participants did not have a diagnosis of autism spectrum disorder. Investigated the ability of two families to learn functional assessment skills and to create interventions. One family was immediately successful, whilst the second needed additional help.
Goodman 1984	Only 10% of participants had a diagnosis of autism spectrum disorder, no sub-analysis of these participants was carried out. 71 participants were assigned to an experimental parent-training group (n35) or a community preschool contrast group (n36). Both groups made gains, IQ remained stable.
Harris 1981	No control group, both arms of the study employed an identical treatment. 11 families were randomly assigned to two groups of parent training. The two groups did not differ in the type of intervention but in the context of their assessments (either home or laboratory). Parent training was successful in both groups; laboratory versus home assessments yielded no difference.
Harris 1982	Multiple baseline design across two groups, no concurrent control group. 11 families were randomly assigned to two groups to receive behaviour and speech modification training. Both parents and children received benefits from the parent training.
Harris 1986a	No control group, retrospective follow-up study. A follow-up questionnaire was administered to 30 families who had received parent training. Retrospective parental evaluations were all positive.
Harris 1986b	No control group, retrospective follow-up study. 30 out of a possible 40 families who had received parent training responded to a retrospective questionnaire. Parents reported encouraging improvements in their children.
Holmes 1982	Retrospective study with a non-concurrent control group. 16 families views were obtained concerning a parent-training programme were investigated. Parents viewed their treatment favourably.
Howlin 1973	No control group. 12 case studies involving parents as co-therapists are presented.
Howlin 1981	Not concurrent controls (two split-time controls). 16 families were involved in parent training intervention. Two control groups were matched to the experimental groups, one for the first 6 months and one for the remainder of the study. The experimental group was found to make rapid linguistic improvements.
Howlin 1987	Non random treatment allocation. 16 participants were involved in the parent focused treatment, short-term (n = 14) and long-term (n = 16) controls received no treatment. The principal therapists were parents themselves who played a major role in designing and carrying out the treatment programmes. The outcome is described in terms of the progress made by individual children. The results from this home based approach to the treatment of autistic children are presented as clear cut in indicating the benefits that stemmed from the intervention programme.
Hungelmann 2001	No control group. 6 families were involved in a TEACCH intervention. Child participants demonstrated significant gains.
Huynen 1996	Single case study, no control group. One family with an autistic child with three other families received planned activities training. Intervention gains were achieved and maintained for 6 months.
Iacono 1998	Two case studies, no control group. Two families with autistic children with three other families received a parent implemented language intervention. Following treatment parents used more direct methods of communication.
Ikeda 1974	No control group. Describes a treatment program for 6 autistic children and their mothers. It is concluded that group therapy combined with individual therapy is effective.
Kaiser 2000	Multiple baseline, no control group. Examined the effects of Enhanced Milieu Teaching (EMT) on 6 families. Positive effects were observed.
Kane 1976	No control group. 16 families with learning disabled children took part in a parent-training programme. Parents were generally successful in meeting the objectives of the programme.
Koegel 1978	Multiple baseline, non random allocation. In experiment one four parents received brief parent training, this training proved to be effective in the short term but did not generalise.
Koegel 1984	Appears to have a control group but lacks data. Participants were assigned on a random basis to receive either parent training or a clinician based intervention. However, very little data is available.

Characteristics of excluded studies (Continued)

Koegel 1999	No control group. Six families took part in a parent training group. Results found that children who had highly favourable outcomes exhibited more spontaneous self-initiations at pre-intervention.
Koegel et al 1996	No primary (child) outcome data, 3 of the 17 children aged over 7 years. Random allocation to individual target behaviour group (ITB) or pivotal response training (PRT). Parent child interaction measured using four outcomes; happiness, interest, stress, communication style. Parents in the PRT group showed more positive interactions than those in the ITB group. Results suggest that parent training may have broad effects; extending beyond the specific treatment procedures, the parents are taught.
Krantz 1993	Single case study. Three families took part in parent training only one under family had a child under the age of 7. Data showed that the home-based intervention produced increases in children's engagement and social initiations and decreases in disruptive behaviour.
Laski 1988	Multiple baseline design. 8 families took part in parent training, 5 were under the age of 7. A small comparison group of normally functioning children was used. Autistic children made treatment gains.
Lee 1992	No control. Three autistic children and their parents participated in a five-week home based parent-training program. The primary purpose of this study was to improve parent-child interaction. The results suggest that intensive parental involvement is the requirement of the highly successful training program.
Lerman 2000	Multiple baseline design. Three families took part in parent training; one child was over the age of 7. Treatment outcome was varied.
Lord 1989	No control group. Longitudinal comparisons were made of intelligence and developmental quotient (IQ/DQ) scores for 3 age groups of 70-72 autistic children aged 2-3, 4-5, and 6-7 yrs at initial assessment and reassessed at least 2 yrs later who were receiving TEACCH intervention.
Lovaas 1987	Non-random allocation. Experimental participants (n19) received 40 hours per week of intensive ABA, control group 1 participants (n19) received 10 hours a week of intensive ABA. The parents, control group 2 participants (n21) received no treatment. In the experimental and control 1 group parents worked as part of the treatment team throughout the intervention; they were extensively trained in the treatment procedures so that treatment could take place for almost all of the children's waking hours.
Love 1990	No control group. Two autistic children were treated for specific fears. Children were exposed gradually to fearful situations, with mothers serving as therapists and reinforcers. Assessments with one child showed maintenance of treatment effects.
Luiselli 2000	No parent training intervention. 16 families were analysed retrospectively according to intensity of treatment. All demonstrated significant changes on six developmental domains but there were no significant differences between age groups.
Marcus 1978	No control, descriptive study. 10 families took part in parent training. Significant positive changes occurred in teaching effectiveness.
Mayo 1997	The participating children were aged over 7 years. 16 families took part in parent training; only 4 children who took part were aged under 7 years. Results indicated that the parents' achieved their selected behavioural goals.
McClannahan 1982	Descriptive study, no control group. Describes a parent-training paradigm that enables parents to serve as home tutors and therapists for their own autistic children.
McEachin 1993	Non-random treatment allocation. The 38 families that took part in the Lovaas (1987) study are followed up, (mean age 13 Years). Results suggested that behavioural treatment may produce long-lasting and significant gains.
Micheli 1999	No control group. 23 families subscribed to the parent-training group. The parent training was useful but not sufficient.
Moran 1991	No control group. Described an education program designed to assist parents in teaching adaptive behaviour skills to their 8 autistic children.
Mudford 2001	Retrospective follow-up study, no control group. The authors summarise child and program data from 75 children with autism receiving early intensive behavioural intervention in the UK.

Characteristics of excluded studies (Continued)

Neef 1995	Did not randomly allocate participants. A pyramidal model of parent training by peers was compared to training by a professional with 26 parents of children with autism. Both types of training increased parental and child performance.
Ono 1994	No control group. 17 families received the TEACCH programme.
Ozonoff 1998	Non-random treatment allocation. 22 families received the TEACCH programme, the experimental group (n11) had additional parent training. The experimental group improved significantly compared to the controls.
Panerai 2000	Participating children were aged over 7 years. Investigates and describes the effects of the TEACCH system on 54 families.
Schopler 1971	Descriptive study, no control group. Highlights the benefits of parental participation from clinical experience.
Schopler 1981	Retrospective study, no control group. Describes the effects of a treatment project involving parent training on 10 families.
Schreibman 1991	No primary (Child) outcome measures, children over 7 years of age. 19 participants, 5 involved in both arms of the study. 24 participants then were randomised to receive either individual target behaviour training (ITB) or pivotal response training (PRT). 120 undergraduates who served as judges were asked to rate positive affect of the participants as they worked in one-on-one training sessions with their children. Results indicate that participants implementing the PRT procedure were rated as exhibiting significantly more positive affect than those participants implementing the ITB procedure. Results also support the hypothesis that the interactions inherent in the PRT procedures may represent more natural parent-child interactions and are more pleasant for the parents to conduct than the highly structured interactions associated with the ITB form of treatment.
Shaddock 1990	No primary (Child) outcomes. 26 families were randomly allocated to either parent training or non-directive support. There was evidence to suggest that the parent training group was successful in implementing some behaviour management techniques, and in teaching parents certain basic information about how families function.
Sheinkopf 1998	Retrospective study with no random allocation of participants. Evaluated the impact of intensive behavioural treatment on the development of young autistic children he treatment reported in this study was home based and was implemented by parents The groups did not differ on pre-treatment IQ. Participants receiving the experimental treatment had significantly higher post treatment IQ scores.
Sherman et al 1988	Participants were initially randomly assigned to group. Participants, however, were then matched according to level of functioning. Children were assessed 2 months prior to intervention, during the six month treatment period, and at a two month follow-up. The home-based group consisted of five children with a mean age of 6 years 1 month and I.Q. of 48 (Stanford-Binet or Merrill Palmer) The Outpatient group consisted of 5 participants with a mean age of 4 years and 7 months, and an I.Q. of 60 (Stanford-Binet or Merrill Palmer). The Residential group consisted of 5 participants with an average age of 4 years 9 months and an I.Q. of 59 (Stanford-Binet or Merrill Palmer). Child outcomes consisted of behavioural observations, Hung Functional Behavioural Checklist, Developmental Checklist. There were no parental outcomes.
Short 1984	No control group. This study describes an attempt to evaluate 15 families involved in the TEACCH programme as it functions in an ongoing clinical service.
Sirbasku-Cohen 2001	No control group. A subset of parents from the descriptive study (n = 12) participated in an 8-session parent group with a family strengths-based approach. There were not any significant changes in family strengths.
Smith 2000b	Multiple baseline, no control group. Examined parent-directed, intensive early intervention for six families. Results indicated that 5 of 6 children rapidly acquired skills when treatment began, but only 2 clearly improved on standardised tests at the 2-3 yr follow up.
Strain 2000	No control group. Data from 6 families participating in An Alternative Program for Preschoolers and Parents (LEAP) early intervention model is described.
Sucuoglu 1994	No control group. 11 mothers completed the training program. Results showed that mothers made gains during the training program. Significant differences were found between pre- and post-test scores.
Thorwarth 1982	No control group. 11 families participated in the Rutgers Parent Training Project (RPTP). Participants were randomised to two identical training programmes. Two assessments were made between 3 and 9 months pre-intervention, and one post intervention.

Characteristics of excluded studies (Continued)

Characteristics of ongoing studies

Study	Elder 1998
Trial name or title	
Participants	Fathers of children with autism.
Interventions	Training fathers and Fathers training other family members.
Outcomes	
Starting date	1998 - 2003
Contact information	Dr. J. H. Elder University of Florida
Notes	

ADDITIONAL TABLES

Table 01. Child Outcomes - Jocelyn et al 1998

Outcome Measure	DIM [CI]	Significance (p)
Autism Behaviour Checklist (psychologist completed)	4.4[-4.15,12.95]	p=0.03
Autism Behaviour Checklist (parent completed)	-3.50[-14.78,7.78]	p=0.5
Early Intervention/Preschool Developmental Profile - Perceptual/Fine motor	1.10[-1.76,3.96]	p=0.5
Early Intervention/Preschool Developmental Profile -Cognition	-0.30[-3.12,2.52]	p=0.8
Early Intervention/Preschool Developmental Profile - Language	-4.20[-7.41,-0.99]	p=0.01
Early Intervention/Preschool Developmental Profile -Social/Emotional	2.50[-0.42,5.42]	p=0.09
Early Intervention/Preschool Developmental Profile - Self-Care	1.70[-1.26,4.66]	p=0.3
Early Intervention/Preschool Developmental Profile - Gross Motor	1.80[-1.15,4.75]	p=0.2

Table 02. Child Outcomes - Smith et al 2000

Outcome	DIM [CI]	Significance (p)
I.Q Stanford-Binet or Bayley	16.82[0.58,33.06]	p=0.04
Merrill-Palmer	15.16[0.14,30.18]	p=0.05
Reynell (comprehension)	9.87[-4.66,24.40]	p=0.18
Reynell (expressive)	8.30[-8.25,24.85]	p=0.3
Reynell (total)	26.07[-3.04,55.18]	p=0.08
Vineland Adaptive Behavior Scales (Communication)	7.10[-10.78,24.98]	p=0.4
Vineland Adaptive Behavior Scales (Daily Living Skills)	-0.67[-16.64,15.30]	p=0.9
Vineland Adaptive Behavior Scales (Socialisation)	-2.59[-18.15,12.97]	p=0.7
Vineland Adaptive Behavior Scales (Composite)	2.69[-14.84,20.22]	p=0.8

Table 02. Child Outcomes - Smith et al 2000 (Continued)

Outcome	DIM [CI]	Significance (p)
Child Behaviour Checklist - parental rating (composite)	2.56[-4.36,9.48]	p=0.5
Child Behaviour Checklist - teacher rating (composite)	-1.94[-7.64,3.76]	p=0.5
Parental Rating of Child Progress (composite)	0.05[-0.66,0.76]	p=0.9
Parental Rating of Child Workload	0.25[-3.19,3.69]	p=0.9
Child Stress	-0.50[-1.55,0.55]	p=0.4

Table 03. Parental Outcomes - Jocelyn et al 1998

Outcome Measure	DIM [CI]	Significance (p)
Stress Arousal Checklist (Stress) - Mother	1.90[-0.63,4.43]	p=0.14
Stress Arousal Checklist (Stress) - Father	2.20[-0.91,5.31]	p=1.17
Stress Arousal Checklist (Arousal) - Mother	-0.30[-3.28,2.68]	p=0.8
Stress Arousal Checklist (Arousal) - Father	1.90[-0.87,4.67]	p=0.18
Family Assessment Measure - Mother	-1.90[-4.78,0.98]	p=0.2
Family Assessment Measure - Father	2.50[-0.87,5.87]	p=0.15
TRE-ADD Autism Quiz -Mothers	-1.70[-3.21,-0.19]	p=0.03
TRE-ADD Autism Quiz - Fathers	-1.50[-3.17,0.17]	p=0.08
TRE-ADD Autism Quiz - Child Care Workers	-2.70[-4.70,-0.70]	p=0.008

Table 04. Parental Outcomes - Smith et al 2000

Outcome Measure	DIM [CI]	Significance (p)
Parental Stress	1.52[0.40,2.64]	p=0.008
Parental Rating of Treatment Quality	0.19[-0.43,0.81]	p=0.5
Parental Rating of Workload	1.09[0.47,1.71]	p=0.0005

GRAPHS AND OTHER TABLES

This review has no graphs.

INDEX TERMS

Medical Subject Headings (MeSH)

Autistic Disorder [therapy]; Child; Child, Preschool; Early Intervention (Education); Parent-Child Relations; Parenting; Randomized Controlled Trials; Treatment Outcome

Medical MeSH check words

Humans

COVER SHEET

Title	Parent-mediated early intervention for young children with autism spectrum disorder
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Contribution of author(s)	Helen McConachie and Val Randle wrote the original protocol; Tim Diggle was chiefly responsible for searching, trial selection, data extraction and analysis. The final writing of the review was carried out by all three reviewers.
Issue protocol first published	2002/1
Review first published	2003/1
Date of most recent amendment	28 February 2003
Date of most recent SUBSTANTIVE amendment	29 January 2002
What's New	Information not supplied by author
Date new studies sought but none found	Information not supplied by author
Date new studies found but not yet included/excluded	Information not supplied by author
Date new studies found and included/excluded	Information not supplied by author
Date authors' conclusions section amended	Information not supplied by author
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DOI	10.1002/14651858.CD003496
Cochrane Library number	CD003496
Editorial group	Cochrane Developmental, Psychosocial and Learning Problems Group
Editorial group code	HM-BEHAV